

All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

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We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: [Feedback form](#)

Family Carer Advocacy Resource

What is advocacy?

“Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocacy promotes social inclusion, equality and social justice.” (The Advocacy Charter, 2018) .

Some people with a learning disability, autism or both may be able to self-advocate. Disability Rights UK defines self-advocacy as “The ability to speak-up for yourself and the things that are important to you. Self-advocacy means you are able to ask for what you need and want and tell people about your thoughts and feelings. Self-advocacy means you know your rights and responsibilities, you speak-up for your rights, and you are able to make choices and decisions that affect your life.”



Key Message

All types of advocacy are of equal value. What advocacy is used, and when, depends on your relative and the situation. What is common to all types of advocacy is that your relative is always at the centre of the advocacy process

For more information about what advocacy is,



- [The Advonet Group](#)
- [Cloverleaf Advocacy](#)
- [Warrington Speak UP](#)

Family Carer Advocate

Even if your relative is able to self-advocate, there may be situations when additional support may be beneficial. This could be in partnership with a family carer advocate (you or a family member), informal advocacy (a friend) or support from a professional independent advocate because there is a statutory (legal) entitlement, and the appropriate advocate will have specialist training in a specific area such as the Mental Health Act.

What your relative can expect from a professional independent advocate

Read how advocates from the Advonet Group hold themselves accountable by providing clear information about what support they are going to provide, how they will provide it and by when, whilst always considering ways to support people to develop their self-advocacy skills.

[Click here to watch a video from The Advonet Group explaining what self advocacy is](#)

[Use this self-advocacy pack](#)

[Visit Advonet's self-advocacy webpage for more information and resources](#)

There is no formal definition for family carer advocacy but the importance of their involvement, either alongside their relative or on behalf of their relative is acknowledged, for example in Acts such as the Mental Capacity Act.

[Click here to read the Advonet Group's Community Advocacy Agreement](#)

[Click here to read the Advocacy QPM Code of Practice](#)



Advocacy Charter

Currently, advocacy is not regulated but most advocacy organisations have signed up to the NDTi Advocacy Charter and NDTi Advocacy Quality Performance Mark (QPM). There is a cost attached to qualifying for the NDTi Advocacy QPM and for some small organisations this may be a barrier, despite providing a good quality service.

[Click here to read more about the Advocacy Quality Performance Mark](#)

[You can check the quality of the service you and/or your relative is receiving using this assessment book](#)

[Click here to read the Advocacy Charter](#)

Who funds advocacy and how this impacts on your relative

The responsibility to fund statutory independent mental health advocacy (IMHA) lies with the local authority where a service is located. This means that if your relative's hometown is London, but they are currently in a mental health service in Leeds, the advocacy they receive will be from an organisation in Leeds.









Following discharge from a mental health service, if your relative is entitled to ongoing statutory advocacy but they are now in a different authority, they will have to be referred to a local service and develop a relationship with a new advocate.

Within each authority, different organisations will have the contract to provide different types of advocacy to different services. This can lead to disjointed advocacy for your relative. For example, if they require support from an Independent Mental Health Act (IMHA) Advocate and an Independent Mental Capacity Act (IMCA) Advocate but two different organisations have been appointed to provide each type of advocacy on one hospital ward, your relative could find themselves with two advocates from two different organisations.






Independent hospitals do not always facilitate access to statutory advocacy and the advocacy they fund may be seen to be in house. In house advocacy means that the advocate works for and is paid by the independent hospital. This can lead to concerns about whether the advocate can truly be considered independent, e.g. they may be raising a concern on behalf of your relative about the organisation which pays their salary. Or if they are the only advocate representing all the people on one ward there may be a conflict of interest. If an independent hospital does not facilitate your relative's access to statutory advocacy e.g. an IMHA, you can remind them that it is your relative's right to access this support and that they have a responsibility to facilitate access to this.

How can an advocate help?

An advocate can help and support a person to:

-  speak up for themselves or give their views
-  understand the process they are going through, their rights and what choices are available to them
-  be part of an important decision which is being made about them
-  prepare for and take part in meetings and tribunals
-  raise queries or concerns [\(Read this guidance from Voiceability which provides information for advocates about challenging decisions or actions with or on behalf of people\)](#)
-  access information in the format which is most suitable
-  access services that can support them
-  provide information and signpost people to other helpful services.

An advocate should not:

-  give their personal opinion or advice
-  solve problems and make decisions on somebody's behalf without first asking / involving them
-  tell people what to do
-  make judgements
-  offer counselling

Instructed advocacy

Instructed advocacy means your relative can independently communicate their likes, dislikes, wishes, feelings, values and beliefs as well as the actions they would like an advocate to take, for example:

- write a letter on their behalf
- represent them in meetings
- contact professionals

People who can instruct an advocate have been assessed as having the capacity (ability) to understand the role of an advocate and how they can represent them.

Non-instructed advocacy

If your relative is entitled to statutory advocacy but has been assessed as lacking capacity (ability) a non-instructed advocacy approach will be used. "Non-instructed advocacy is... taking affirmative action with or on behalf of a person who is unable to give a clear indication of their views or wishes in a specific situation. The non-instructed advocate seeks to uphold the persons rights, ensure fair and equal treatment and access to service, make certain that decisions are taken with due consideration for their unique preferences and perspectives." (Henderson, 2006). There are 4 key approaches used for non-instructed advocacy:

- Rights-based approach. Your relative has certain fundamental human rights that can be defined and measured, e.g. right to family life
- Person-centred approach (find out more)
- Watching brief approach (find out more)
- Witness/observer approach. By spending time with your relative an advocate observes what they like/don't like, what makes them happy and equally if there is anything of concern which needs to be addressed.

Non-instructed advocacy considers the following questions::

- What is life like for your relative? What is important to them? What might their wishes, feelings and desires be?
- What are their rights?
- What information do other people (e.g. their family carers, other family members and friends) know about your relative's past or present preferences
- What responsibilities do other people (e.g. family carer) or organisations (e.g. social services) have towards your relative?
- Is your relative being treated fairly?
- How can your relative's involvement in decisions made about them and their life be increased?

Non instructed advocacy should ensure your relative's voice is heard if they have been assessed as lacking capacity. To do this they should be able to spend time with and observing your relative, speak to people who know them, and access relevant records about care and treatment. Despite this, family carers report that it is difficult to access skilled, non instructed independent advocates.

[Click here to read the non-instructed advocacy best practice guidance](#)

[Click here to read Josie's story](#)

Types of advocacy

Statutory Advocacy

Statutory advocacy means a person is legally entitled to an advocate because of their circumstances. The local authority has a duty to ensure statutory advocacy is available to people in their area. The following are Statutory Advocacy services:

Independent Mental Capacity Advocacy (IMCA)

If your relative has been assessed as lacking mental capacity an IMCA can provide support when a specific decision is required at a specific time including:

- When there is no family carer, other family member, friend or unpaid person to provide support
- There is a disagreement about what is in your relative's best interests, and family or friends have been deemed 'inappropriate to consult'
- There are allegations, suspicions or proved incidences of abuse by the family carer, other family members or friends
- Giving or withholding serious medical treatment (e.g. cataract operation)
- A proposed change or review of living circumstances (e.g. admission to hospital)
- Safeguarding, e.g. financial or physical abuse

Care Act Advocacy

For further information read Making Decisions: The IMCA Service from the office of the Public Guardian (OPG):

[Click here to read more and/or visit this SCIE link](#)

The Care Act 2014 requires the local authority to involve your relative in decisions about their care and support needs. However, if they will have substantial difficulty being involved in any of the following processes:

- A social care assessment or review
- Agreeing a social care support plan
- A safeguarding enquiry or process

and they do not have a family carer, other family member, or friend who is able and willing to advocate on their behalf, they have the right to a Care Act Advocate. The Care and Support Statutory Guidance states that "Many of the people who qualify for advocacy under the Care Act will also qualify for advocacy under the Mental Capacity Act. The same advocate

[Watch this video explaining the Care Act](#)
[and read this factsheet for more information](#)

The same advocate can provide support as an advocate under the Care Act as under the Mental Capacity Act. This is to enable the person to receive seamless advocacy and not have to repeat their story to different advocates". "By having the same advocate for all IMCA referrals we were able to ensure that Carol received advocacy support from someone who understood her history, had knowledge of her needs and who had established a positive working relationship with the wide range of professionals involved." (Warrington Speak UP – [Read Carol's full story](#))

Independent Mental Health Advocacy (IMHA)

Your relative is entitled to an IMHA if they are:

- Detained (sectioned) under the MHA
- Under a Community Treatment Order (CTO)
- Subject to a Guardianship Order
- Conditionally discharged

An IMHA cannot provide support for your relative if they are:

- Taken to a place of safety under the MHA
- Informally held for a period of up to 72 hours under emergency 'holding powers' using Section 5 of the MHA which is to allow for a formal assessment of detention to be completed

Deprivation of Liberty Safeguards (DoLS) 2009

If your relative is being deprived of their liberty under the Mental Capacity Act, an IMCA can be appointed to protect their human rights and make sure the deprivation is:

- lawful
- reasonable
- in their best interests
- A Section 39A IMCA will be instructed when there is an assessment in response to a request for a standard authorisation, or a concern about a potentially unauthorised DoL

Relevant Person's Representative (RPR)

A Relevant Person's Representative is responsible for protecting a person's interests if:

- they have been assessed as lacking capacity to make some decisions for themselves, and
- they have been deprived of their liberty to prevent them from coming to harm
- a RPR can be a family carer, other family member or friend
- a section 39C IMCA can cover the role of the person's RPR if there is a gap between appointments
- a section 39D IMCA can support your relative or the RPR if there is a standard authorisation in place

Paid Relevant Person's Representative (PRPR)

- The local authority will appoint a PRPR if there is no family carer, other family member or friend available to take on this role
- A PRPR has the same responsibilities as an RPR

The responsibilities of the RPR or RRPR:

- Regular contact with the person they are representing
- Checking that any deprivation of liberty remains legal

More information on the responsibilities and processes of an RPR or PRPR:

[Click here to read a guide from the Department of Health](#)

[Click here to read Julia's story](#)

- Making sure that the person's wishes, feelings, values and beliefs are upheld
- The support provided by the RPR or RRPR must be completely independent from the providers of the service your relative is receiving

Rule 1.2 Representative

A Rule 1.2 Representative supports anyone who is being deprived of their liberty in a community or domestic setting who has been assessed as lacking capacity and needs someone to advocate on their behalf about consent to restrictions on their freedom. Usually a social worker will decide whether the role of Rule 1.2 Representative is a family carer or friend (unpaid) or a professional independent.

NHS Complaints Advocacy

NHS Complaints Advocates help people raise a complaint about any service provided or funded by the NHS including:

- GPs
- hospitals
- mental health services
- pharmacies
- opticians
- dentists
- ambulance services
- nursing homes
- care homes
- home based care packages

Read this case study from the Advonet group: [Click here to read the case study](#)

The advocate:

- Helped to identify all options available to the person they were representing
- Supported their client through the process ensuring there was no further deterioration in their mental health due to the stress related to making a complaint
- Kept the organisation involved up to date with any delays because of their client's mental health to make sure this did not impact on the complaints procedure

Non-Statutory Advocacy

Non-statutory advocacy means there is no legal entitlement to an advocate and therefore no obligation for local authorities to provide funding. Individual local authorities can decide what non-statutory advocacy – if any – they will fund. This type of advocacy is often provided by charities who work in specific areas, e.g. [The Challenging Behaviour Foundation](#) who specialise in supporting families and their relatives who have a severe learning disability and behaviour described as challenging.

Citizen Advocacy

Citizen Advocates provide one-to-one support to help people tackle any issues they are facing. Citizen Advocates may provide support in person, by telephone or by email and help people to access information, speak up and get their voice heard.

[Watch the Advonet Group's Meet the Citizens Advocates video to learn more](#)

Peer Advocacy

Peer Advocates are people, often volunteers, with lived experience of using health and social care services. They share their experience and provide practical support and encouragement. Peer advocates are matched with someone who has similar needs and issues to support them to develop new skills and gain confidence.

[Read about the peer advocacy provided by The Challenging Behaviour Foundation](#)

Group Advocacy

Group Advocacy brings together people with similar needs and issues to support each other. These groups give people the opportunity to share experiences and work in partnership to raise joint concerns. Sometimes the group has a facilitator who supports the running of the group and sometimes these groups are self-supporting.

Carers Advocacy

NHS England defines a carer as “...anyone, including children and adults who looks after a family member, partner or friend who needs help because of illness, disability, or a mental health problem and cannot cope without their support. The care they give is unpaid...”.

Carers Advocates can help family carers:

- to understand their rights and how to exercise them
- access a Carers Assessment
- communicate their own needs to people making decisions
- by attending meetings
- raise a concern or make a complaint
- by signposting to other services that might be available to help them

Legal Advocacy

You may hear the phrase legal advocate sometimes used to describe a lawyer. This role is different to the type

Further information



Read this guide from The Challenging Behaviour Foundation about what commissioners should consider when commissioning advocacy services for people with a severe learning disability:

- [Click here to read the guide](#)

This factsheet from Cloverleaf Advocacy provides answers to frequently asked questions about advocacy:

- [Click here to read the factsheet](#)

Read what the Care Quality Commission says about the relationship between person-centred care and support and advocacy:

- [Click here to read more](#)

Last reviewed: August 2025

We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email info@theCBF.org.uk, or visit our website: www.challengingbehaviour.org.uk